

## REVIEW

# The adolescent with a chronic condition. Part I: developmental issues

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The prevalence of chronic conditions among adolescents is difficult to assess due to the lack of quality data focusing specifically on this age group, as well as the diversity in methodology and definitions used. However, surveys carried out by self administered questionnaires among in-school adolescent populations indicate that around 10% of adolescents suffer from such a condition. The aim of this paper is to analyse the reciprocal effects of chronic conditions and adolescent development by reviewing the effect of chronic disease on growth and puberty and on psychosocial development, and the effect of developmental issues on the course and management of chronic disease.

questionnaires in France, Switzerland, and Canada<sup>5–7</sup> indicate that around 10% of adolescents suffer such a condition. Note that the validity of these data is limited as school based surveys may not include those with severe physical or mental limitations who either stay at home or live in special institutions. Globally, rates seem to be higher among males, among rural residents, among less privileged social classes, among impoverished areas within countries, and among adolescents living in less educated families.<sup>1–8</sup>

The management of any chronic condition during adolescence, a time of rapid growth and physiological changes accompanied by important individuation and socialisation processes, constitutes a major challenge for the individual, his/her family, and the healthcare team. The purpose of this paper is to review the impact of chronic conditions on the bio-psychosocial processes of adolescence.

For this purpose, a non-categorical approach has been used, as defined by Stein and Jessop.<sup>9–10</sup> These authors suggest that there are commonalities that cross disease categories and that, while there are issues that are specific to each disease, the commonalities can be used to increase the experience of the practitioner. These cross-disease commonalities apply not only to children and adolescents, but also to their families.<sup>3</sup> Finally, although this paper focuses mainly on the issue of somatic diseases, its content does apply to a large extent to any chronic condition, including mental illness and chronic disability.

In 2001 the Department of Child and Adolescent Health of the World Health Organisation (WHO) asked the authors to write a review and discussion paper on the clinical management of chronic conditions in adolescents (Obligation no. HQ/01/407101). After agreeing on the outline of the main topics to be discussed, the authors sought for the most relevant literature in the field, focusing whenever possible on evidence based papers. For this purpose on-line database searches (including Medline, Embase, and PsycINFO) and relevant grey literature were used. The present paper is the first of a two part shorter version of the WHO manuscript.

## EPIDEMIOLOGY

The prevalence of chronic conditions among adolescents is difficult to assess due to the lack of quality data focusing specifically on this age group, as well as the diversity in methodology and definitions used.<sup>1–2</sup> There are many issues involved in the definition of chronic health conditions, including duration, age of onset, whether it is congenital or acquired, limitation of age appropriate activity, visibility, expected survival, mobility, physiological functioning, cognition, emotional/social impairment, sensory functioning, communication impairment, course, and uncertainty.<sup>3</sup> If conditions such as mild asthma or correctable vision conditions are included in the definition, the prevalence rate for chronic conditions in adolescence can be as high as 15%. If the definition is narrowed, the prevalence is reduced by half.<sup>4</sup>

Raw data regarding the prevalence of chronic conditions among in-school adolescents according to surveys carried out by self administered

## THE RECIPROCAL EFFECTS OF CHRONIC CONDITION AND ADOLESCENT DEVELOPMENT

The development of the individual during this period of life can be divided into three main stages: early, middle, and late adolescence, each characterised by specific biological, psychological, and social steps. While any chronic condition can potentially affect these developmental processes, the reverse is true—that is, both physiological change and psychosocial adjustments can have an impact on the disease (table 1).

### Effect of chronic disease on growth and puberty

Delayed growth and puberty is common to most chronic illnesses, although more frequent in those where malnutrition and chronic inflammation are most common (for example, bowel disorders, cystic fibrosis). This delay may be transient, with later catch-up growth producing normal adult heights, although permanent

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**Table 1** Reciprocal effects of chronic illness or disability and adolescent development<sup>68-72</sup>

Effects of chronic illness or disability on development	Effects of developmental issues on chronic illness or disability
<p><b>Biological</b></p> <p>Delayed/impaired puberty</p> <p>Short stature</p> <p>Reduced bone mass accretion</p> <p><b>Psychological</b></p> <p>Infantilisation</p> <p>Adoption of sick role as personal identifier</p> <p>Egocentricity persists into late adolescence</p> <p>Impaired development of sense of sexual or attractive self</p> <p>Impaired development of cognitive functions and information processing</p> <p><b>Social</b></p> <p>Reduced independence at a time of when independence is normally developing</p> <p>Failure of peer relationships then intimate (couple) relationships</p> <p>Social isolation</p> <p>Educational failure and then vocational failure; failure of development of independent living ability</p>	<p><b>Biologically</b></p> <p>Increased caloric requirement for growth may negatively impact on disease parameters</p> <p>Pubertal hormones may impact on disease parameters (e.g. growth hormone impairs metabolic control in diabetes)</p> <p><b>Poor adherence and poor disease control due to:</b></p> <p>Poorly developed abstract thinking and planning (reduced ability to plan and prepare using abstract concepts)</p> <p>Difficulty in imagining the future; self-concept as being "bullet proof"</p> <p>Rejection of medical professionals as part of separation from parents</p> <p>Exploratory (risk taking) behaviours</p> <p><b>Associated health risk behaviours</b></p> <p>Chaotic eating habits may result in poor nutrition</p> <p>Smoking, alcohol and drug use often in excess of normal population rates</p> <p>Sexual risk taking, possibly in view of realisation of limited life span</p>

growth loss may also occur. Large birth cohort studies such as the British 1958 birth cohort of 12 537 subjects found that physical chronic illness of any type in childhood and adolescence made no difference to adult height, whereas children with psychosocial chronic illnesses (for example, enuresis, mental health problems) were 1 cm shorter as adolescents and adults, a finding which remained significant when controlling for confounders such as socioeconomic status.<sup>11</sup>

Biological, psychological, and social development are highly inter-related and the timing of one may affect development in other domains. The psychological and social effects of delayed puberty should not be ignored. Delayed puberty may result in low self-esteem in boys and in difficulty in separating from parents due to apparent immaturity. Adolescents affected by delayed puberty may be treated as less mature than real age by adults and peers, and face difficulties in getting work due to apparent immaturity.<sup>12</sup>

### Effect of chronic disease on psychosocial development Wellbeing and mental health

The wellbeing of chronically ill adolescents is determined largely by the severity of the disease and the amount of treatment required, however it is also determined by the psychological and social complications that may accompany such conditions.<sup>13</sup> The variable nature of such complications is shown in the sometimes contradictory findings in different studies: in a meta-analysis review, Lavigne and Fairer-Routman<sup>14</sup> found that the risk of psychological adjustment problems can vary across disease groups—young people with chronic conditions are likely to display internalising symptoms than healthy controls. Other studies<sup>15</sup> found that chronically ill girls were more likely to have emotional problems than their healthy counterparts, but that the same was not true for boys. Ill adolescents are more likely to develop psychiatric and behavioural disorders,<sup>16</sup> may show a higher prevalence of at least one psychiatric diagnosis than healthy controls,<sup>17</sup> and are more likely to be depressed or have low self-esteem.<sup>18</sup> In type 1 diabetes, young adults appear to be as psychologically well adjusted as their healthy peers,<sup>19</sup> whereas young people with asthma appear to feel lonely, unhappy, or depressed and suffer from somatic symptoms significantly more often than healthy controls.<sup>20</sup>

### Cognitive capacities

With the exception of most inherited metabolic diseases, it is unlikely that chronic illness affects the basic neuronal maturational mechanisms that underlie the development of abstract thinking capabilities in adolescence, although little data exists on this area. Certain chronic illnesses such as diabetes and sickle cell disease are known to have long term neuropsychological effects in adolescence, although these are the result of the disease process (hypoglycaemia in diabetes<sup>21</sup> and cerebrovascular accidents in sickle disease<sup>22</sup>) rather than representing a generic chronic illness effect.

In contrast, there is evidence that identity, self-image, and ego-development are affected by chronic illnesses in a generic fashion.<sup>23</sup> This is particularly true when illness is more severe and verbal IQ is higher.<sup>24</sup> Body image and the development of a sense of the sexual sense may also be impaired by chronic illnesses which either distort the physical body (for example, stomas or scars)<sup>25</sup> or require treatments that may be distancing to others.<sup>26</sup> Population based studies show that adolescents with chronic illness report higher body dissatisfaction than adolescents without chronic illness. These body image issues focus particularly on weight and result in higher rates of high risk weight loss practices.<sup>27</sup> Body image issues or dissatisfaction may theoretically impair later sexual function, although population based studies suggest that adolescents with chronic illness have higher rates of sexual intercourse and unsafe sexual practices than healthy controls.<sup>28</sup> It is possible that body image problems may act to increase risk in sexual behaviour.

### Education and school

The issue of school health should be tackled from a broad perspective.<sup>29-30</sup> The first question that arises is related to the information that is given to the school health staff (if existing) and to the teachers and classmates. For understandable reasons, many parents and teenagers are reluctant to disclose some conditions, with the fear that they may become labelled and stigmatised. More commonly, young people, from an understandable wish not to stand out, do not communicate any information on their disease, which may lead to the development of a crisis situation within the school (diabetic coma, cardiac failure, severe asthma attack, etc). Both the parents and the teenagers should be strongly encouraged to disclose information in an appropriate and stepwise manner: the school health nurse or physician should

be fully notified of the situation, whereas the briefing to the teaching staff should be restricted to those pieces of information which they have to know to support the pupil or to cope with critical events.<sup>29–31</sup> This process should be as open as possible and run with the consent, and if possible with the assistance, of the patient. In a regular fashion, information should be exchanged between the healthcare team, the school health staff, and the teachers.

Recurrent illness and the demands of treatment regimens may significantly impact on school attendance and educational achievement, which in turn may result in vocational impairments and loss of financial independence in adult life. Additionally, the developmental imperative for educational attainment may affect chronic illness through conflicts of priorities between chronic illness management and schooling requirements. Young people and their families may prioritise education over treatment during the key educational stages in later adolescence; for example, missed appointments, refusal to do lunchtime treatments, or refusal of regular transfusions in sickle cell disease due to missed school.<sup>32</sup> The way that health professionals deal with the educational system is key in reducing the impact of intensive educational requirements on chronic illness management.<sup>31–33</sup>

Teenagers with chronic conditions are more likely than their healthy peers to miss school due to their condition or to the treatment they need.<sup>34</sup> School attendance may be affected by the severity of the illness, treatment adherence, and psychological problems,<sup>32</sup> but ill young people miss more school days both due to their health problems and because they are more likely to skip school.<sup>7</sup> In fact, adolescents with chronic conditions often miss more school days than can be attributed to their treatment needs.<sup>35</sup> Lost school time ranges from 13% for patients with orthopaedic problems to 35% for those with cancer.<sup>35</sup> Evidence from studies of adolescents with chronic arthritis also shows significantly higher school absence than the general population, and that school absence is associated with decreased compliance with physical treatments and with psychological disturbance.<sup>32</sup>

The issue of absenteeism is of particular relevance: severe chronic conditions often induce frequent hospitalisations and the healthcare team should try to link with specialised in-hospital teachers or establish cooperation with teachers or classmates to allow the patient to cope with the schooling programme.<sup>30</sup> In rare instances, it may be more appropriate to educate some young people in special facilities. However, to avoid discrimination as much as possible, every effort should be made to integrate adolescents with a chronic condition—including those with physical disabilities—into a normal school environment.

The question is to what extent do such educational difficulties have a long term impact? Data from the longitudinal British 1958 birth cohort show that chronic illness in childhood/adolescence resulted in poorer educational qualifications and higher risk of unemployment, particularly in males.<sup>36</sup> However, adolescents with chronic illness followed up into middle age showed no diminution of financial outcomes, except in those from lower socioeconomic classes who had significantly lower life chances and income.<sup>37</sup> This suggests that the deleterious effects of chronic illness on educational and vocational outcomes may be overcome by higher family and professional support. In the clinical arena, the importance of actively helping young people with chronic illness or disability develop independent adult living and vocational skills has been shown in longitudinal follow up studies.<sup>38</sup>

### Family and peer relations

The presence of an adolescent with a chronic condition imposes an increased burden on the parents:<sup>39</sup> the demands

of managing a chronic illness and the restrictions on lifestyle inherent in many disabling conditions increase dependence on the family and carers at a time when this should be decreasing.<sup>40</sup> At the same time, young people may also become excluded from their peer group, particularly in those with taxing medical conditions and those that mark them out as very different (for example, ileostomy).<sup>25</sup> Given the wide range of severity of chronic conditions as well as differences in measuring family functioning, it is once again not surprising that research findings can be conflicting: some families adequately cope with this situation while others are overwhelmed by the problems brought by the condition. Most young people with chronic conditions describe the relationship within their family as good, although their parents tend to overprotect them.<sup>41</sup> Adolescents with cystic fibrosis reveal that family members provide tangible support.<sup>42</sup> While some studies found no differences in family functioning,<sup>39</sup> others indicate that family interaction may be lower in chronically ill young people than among their healthy controls.<sup>43</sup> Mothers of chronically ill children and adolescents may show higher levels of psychopathological symptoms, whereas fathers may not:<sup>44</sup> mothers tend to concentrate on day to day activities and are more likely to show depressive symptoms, while fathers tend to concentrate on long range problems and are more likely to report stress.<sup>16–45</sup> However, according to a Finnish study,<sup>46</sup> only 7% of interviewed parents indicated that having a child with a chronic condition had decreased parental closeness. Similarly, both a Canadian and an American<sup>47–48</sup> study indicate that parents of children with chronic conditions are not at greater risk of marital distress or show differences in marital status compared to parents of normal children. In fact, more adaptive family relationships and parental psychological adjustment are associated with positive psychological adjustment.<sup>49–50</sup>

One of the very best ways for any adolescent to engage in his/her individuation process is to rely on peer relationships.<sup>51</sup> Indeed, peers provide the adolescent with support that enables them to break loose from their parents and adults in general.<sup>41–52–53</sup> Moreover, it is with peers that adolescents exchange a lot of ideas and feelings, and these encounters greatly contribute to identity formation. Adolescents with chronic conditions come as no exception to this rule, and it is thus both important and helpful to encourage all forms of socialisation.

Peer support is crucial during this period of intense socialisation,<sup>42</sup> although the friends of adolescents with chronic illness are often younger and non-disabled.<sup>41</sup> Many young people with chronic illnesses report having excellent peer relationships,<sup>54</sup> and there is evidence that some illnesses (for example, cancer) may even increase peer acceptability.<sup>55</sup>

The healthcare team can promote this process in several ways, such as discussing this issue directly with both the parents and the patient, examining how the organisation and the content of the treatment can be modified according to the adolescent's lifestyle, or encouraging the young person to join informal and formal youth groups such as sports clubs, theatre and music associations, scout organisations, etc.

Self-help organisations which gather the families of individuals with specific diseases can be useful to organise special events such as conferences, outings, and tours, which promote exchanges between adolescents facing similar situations.<sup>56–57</sup>

### Effect of developmental issues on the course and management of chronic disease

#### Impact of growth and pubertal changes

Puberty and the adolescent growth spurt pose a significant caloric and metabolic burden on the healthy adolescent body,

and may destabilise chronic illnesses. The evidence for this is clear in diabetes, where increased growth hormone levels cause insulin resistance,<sup>58</sup> but lacking in other conditions (for example, the more rapid reduction seen in FEV<sub>1</sub> in cystic fibrosis during puberty). Moreover, physicians who are not aware of the rapid growth rate and alteration of the hepatic and renal metabolism during puberty may underestimate the need for proper medication dosage.

### Impact of psychological changes

Due to the crisis inherent to their maturation process, adolescents are often considered as non-compliant, but such a view must not be generalised.<sup>59</sup> Adherence to a treatment regimen requires appropriate cognitive capacities and personal organisation as well as a personal belief that the treatment is required and beneficial.<sup>60</sup> Adherence is maximised when the professional-patient partnership decides management strategies in the light of the health beliefs and personal goals of the patient.<sup>61</sup>

Young people may have difficulty adhering to treatment regimens devised for them by health professionals and parents because of poorly developed abstract thinking, which may manifest as a relatively poor ability to plan and prepare for different situations using abstract concepts; an immature ability to imagine future consequences; and a concept of themselves as "bullet proof" or not vulnerable to the usual rules of life. Together, these cognitive issues may mean that the prevention of long term complications of illness is a poor motivator for compliance.<sup>62</sup> Additionally, adherence may be impaired because of a lack of shared health beliefs and goals with the young person's treating health professionals or family.

### Impact of the socialisation process

The development of peer relationships and self-image issues (clothes, dress, public behaviours, etc) may be in conflict with the demands of chronic illness treatment regimens or the disability resulting from orthopaedic or neuromuscular defects. The extent to which such adolescent issues affect illness management and control will depend on how young people balance competing priorities. For example, modern diabetes regimens include lunchtime injections, which some young people find unacceptable for reasons of "fitting in" or because they prioritise social time over disease control.<sup>63</sup> In chronic illnesses where young people may resort to devices or medication for regular treatment and monitoring, decisions about carrying inhalers (asthma or cystic fibrosis), insulin pens or glucometers (diabetes), or other medications may be influenced by how young people balance competing priorities.<sup>64</sup>

### Exploratory and health related behaviours

Adherence and chronic illness control can be put at risk by developmental needs to explore possible modes of future behaviour, usually derogatively referred to as "adolescent risk taking". Chronically ill adolescents show substance use rates similar<sup>20</sup> <sup>65</sup> or even higher than their healthy controls.<sup>7</sup>

Similarly, a number of studies have shown that young people with chronic illness and disability are not less likely than peers to be sexually active<sup>66</sup> and that age of sexual debut, pregnancy involvement, patterns of contraceptive use, or sexual orientation are little different in those with different chronic conditions and the general population.<sup>67</sup> The visibility of the chronic condition or disability does not appear to affect sexual behaviours in adolescents.<sup>67</sup>

### SUMMARY

Approximately one adolescent out of ten has a chronic condition that somehow limits his or her daily activities. There is substantial evidence that chronic conditions can

affect adolescent development and that adolescent development can have an effect on the condition. Adolescence is a time of rapid changes and turmoil. Teenagers with chronic conditions have an additional burden. However, in comparing them to their healthy peers, there seem to be more commonalities than differences. They need the same guidance and prevention as any other adolescent.

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